

**NEWBORN BLOOD SPOT SCREENING  
LABORATORY**

BC Children's Hospital  
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Place Infant's  
Addressograph/Label Here

## INFORMED REFUSAL: NEWBORN BLOOD SPOT SCREENING

I refuse to consent to my baby receiving the newborn blood spot screening tests listed below.  
I choose this knowing that:

- Newborn screening is considered standard of care for all newborns born in BC and the Yukon.
- Testing for more than 25 treatable conditions is done by taking a few drops of blood from my baby's heel.
- One in 750 babies are born with one of these treatable conditions.
- Babies with these conditions, when found and treated early, have significantly improved health outcomes.
- My baby may look healthy now but could still have one of these treatable conditions.
- If my baby has one of these conditions, and is not screened and treated early, my baby could have serious developmental delay and other health problems, or may even die.

\_\_\_\_\_  
Name of Parent / Legal Guardian First and Last name (please print clearly)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Witness (patient's most responsible health care provider). I watched the parent / guardian sign the refusal form.

\_\_\_\_\_  
Witness First and Last Name (please print)

\_\_\_\_\_  
Witness Signature

\_\_\_\_\_  
Date

The treatable conditions in British Columbia's Newborn Blood Spot Screening Program:

|  |  |  |  |
|--|--|--|--|
| <b>Metabolic Disorders</b>   |  |  |  |
| <b>Amino Acid Disorders:</b>   |  | <b>Fatty Acid Oxidation Disorders:</b>   | <b>Organic Acid Disorders:</b>   |
| <ul style="list-style-type: none"><li>• Phenylketonuria (PKU)</li><li>• Maple Syrup Urine Disease (MSUD)</li><li>• Citrullinemia (CIT)</li><li>• Argininosuccinic Acidemia (ASA)</li><li>• Homocystinuria (Hcy)</li><li>• Tyrosinemia I (Tyr I)</li><li>• Guanidinoacetate Methyltransferase Deficiency (GAMT)</li></ul> |  | <ul style="list-style-type: none"><li>• Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCAD)</li><li>• Long-chain Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)</li><li>• Very-long chain AcylCoA Dehydrogenase Deficiency (VLCAD)</li><li>• Carnitine Uptake Disorder (CUD)</li></ul> | <ul style="list-style-type: none"><li>• Propionic Acidemia (PROP)</li><li>• Methylmalonic Acidemia (MUT) and B12 Deficiency</li><li>• Cobalamin Disorders (Cbl A,B)</li><li>• Glutaric Aciduria Type 1 (GA I)</li><li>• Isovaleric Acidemia (IVA)</li><li>• Biotinidase Deficiency</li></ul> |
| <b>Galactosemia (GALT)</b>   |  |  |  |
| <b>Endocrine Disorders</b>   |  | <b>Sickle Cell Disease and other Hemoglobin Disorders</b>  | <b>Cystic Fibrosis (CF)</b>  |
| <ul style="list-style-type: none"><li>• Congenital Hypothyroidism (CH)</li><li>• Congenital Adrenal Hyperplasia (CAH)</li></ul>  |  |  | <b>Spinal Muscular Atrophy (SMA)</b>   |
|  |  |  | <b>Severe Combined Immunodeficiency (SCID)</b>   |

For health care provider use ONLY: see link for more information: <http://www.perinatalservicesbc.ca/health-professionals/professional-resources/screening/newborn>

- ☐ Fax this refusal form to NBS program 604-875-3836
- ☐ Place copy of this signed form in baby's health record
- ☐ Notify the infant's physician or midwife of the refusal